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Perspectives on challenges and opportunities for birth defects surveillance programs during and after the COVID-19 era

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Abstract

In recent months, various public health measures have been implemented throughout the world in response to the coronavirus disease 2019 (COVID-19) pandemic. This outbreak, and the subsequent containment policies, may have a range of potential short- and long-term impacts on the monitoring and surveillance of other conditions, such as birth defects. In this commentary, we provide a perspective on these potential impacts on birth defects surveillance and analysis. We discuss possible effects on clinical birth defect diagnoses, routine birth defects surveillance system activities, and epidemiologic considerations, as well as opportunities for mitigating the impact of COVID-19. Like many other sectors of public health and medicine, birth defects surveillance programs may be faced with organizational and methodological obstacles in the wake of a changing landscape. A better understanding of these potential challenges faced by birth defects surveillance programs could facilitate better planning and collaboration across programs to overcome barriers to core activities and to prepare for novel opportunities for research and prevention.

KEYWORDS

birth defects, birth defects registry, coronavirus, COVID-19, pregnancy, surveillance

1 | INTRODUCTION

In recent months, widespread person-to-person transmission of the novel coronavirus, SARS-CoV-2, has led to a pandemic of coronavirus disease 2019 (COVID-19). In response, stringent public health measures have been implemented to limit the spread of the virus. There has not yet been much time to fully understand how COVID-19 will affect the core public health function of monitoring and surveillance of other conditions, such as birth defects. In this commentary, we provide a perspective on potential short- and long-term impacts the outbreak, and subsequent containment policies, may have on birth defects surveillance and analysis. A better understanding of the potential challenges faced by birth defects surveillance programs could facilitate better planning and collaboration across programs to mitigate barriers to core activities and to prepare for new opportunities for research and prevention.

2 | IMPACT ON CLINICAL BIRTH DEFECT DIAGNOSES

Birth defects surveillance systems rely on the accurate clinical diagnosis of birth defects at birth or later

(e.g., within the first year of life). There are several reasons to suspect that birth defects may be under-diagnosed in medical visits during the COVID-19 outbreak. Healthcare systems throughout the world are experiencing increased strain due to the influx of suspected and confirmed COVID-19 cases who require various levels of treatment. To address these new challenges in patient load, and to decrease the likelihood of exposure for infants and children, some facilities may attempt to discharge patients more quickly to increase hospital capacity. Shortened stays may reduce opportunities to identify, document, test, and follow-up for birth defects, particularly for mild and/or defects not easily recognizable in early life. It is further possible that nonemergency procedures will be postponed among infants with birth defects, which may affect the availability of post-procedure data that would be used to confirm birth defect diagnoses.

The anticipated strain on the healthcare system may also result in new clinical challenges and increased workloads for clinicians that are not directly involved in treating patients with COVID-19. For example, existing clinical collaborations and resources may become strained (e.g., decreased patient access to social workers and other resources outside of the clinical domain). Providers with a significantly increased workload would have less time to dedicate to pre- and post-delivery care, and it is possible that these changes may result in reduced capacity for thorough examination and documentation of birth defects, both during delivery and throughout infancy and early childhood.

Along with these new clinical challenges, changes in clinical approaches and practice are anticipated. For example, telemedicine has been encouraged to decrease physical contact for providers and patients during the pandemic, and the potential downstream effects on birth defects surveillance are unclear. Although physical examinations via this medium may prove more difficult, there is also a possibility that the quality and specificity of data captured in the electronic medical record (EMR) may actually increase as providers are forced to rely more on EMRs for standard healthcare provision.

In addition to provider-based COVID-19 disruptions on birth defect diagnosis, patients and their families may be forced to make more selective choices regarding infant care than they would have otherwise, such as delaying routine preventive care in order to limit public contact and subsequent risk of SARS-CoV-2 infection. This may influence when and where infant data are collected, likely resulting in further under-diagnosis or under-documentation of birth defects. Similarly, routine care and nonemergency treatment may be delayed by providers for similar reasons and/or to reduce strain imposed by increasing overall patient load, as described above. Specifically, decreases in routine prenatal care visits could result in fewer opportunities to diagnose birth defects prenatally. If so, and/or if there are reductions in the availability of (or the desire for) elective terminations for prenatally-detected cases during this time, there may be an increase in births of infants with severe birth defects; this could impact the observed prevalence for certain defects reported by surveillance programs.

However, despite all of these potential challenges, it is also important to remember that most severe or life-threatening birth defects (e.g., trisomy 13, bilateral renal agenesis) will continue to have a high likelihood of being evaluated, diagnosed, and documented appropriately; therefore, the anticipated impact on surveillance data for these defects should not be significant.

3 | IMPACT ON ROUTINE BIRTH DEFECTS SURVEILLANCE SYSTEM ACTIVITIES

The current pandemic is posing new challenges due to restrictions to working on-site. In March 2020, measures to limit all person-to-person contact were implemented across many regions and jurisdictions worldwide, and it is unknown how long such mitigation strategies will be enforced. These restrictions have created barriers for routine on-site (i.e., at the hospital, birthing facility) review of medical records, which is required for active case-finding programs and passive programs who implement case verification procedures. Further, limited availability of secure computing resources, infrastructure, and data security measures poses challenges. For example, to comply with all necessary requirements of legislative statutes and/or organizational requirements, data use agreements may require personnel to be in a secure location, utilize a virtual private network (VPN) and secure network connection, or other specifications prior to granting access. The requirements (particularly a "secure" environment from which data are accessed) may or may not be possible to ensure when working from home, and online constraints (e.g., home WiFi speed, network capacity) may impact abstraction capabilities and the timeliness of case ascertainment. Given these new barriers to efficiency, it would also not be surprising if such constraints resulted in an increased number of missed birth defects diagnoses occurring during abstraction. Surveillance systems with existing access to medical records for staff working remotely may be less severely impacted. These challenges are not restricted to abstractors, and are likely to impact other routine birth defects surveillance activities, including case identification, record abstraction, clinical review, data quality assurance, and registry management. On a

positive note, these challenges may lead to new opportunities for surveillance programs to develop and/or improve remote access in the long-term.

The United States and other countries are in the process of allocating substantial funding and governmental resources for COVID-19 surveillance and research. It is unclear how this might affect future priorities for birth defects research. As many birth defects surveillance activities depend on fiscal resources from local, state, and federal/national government agencies (e.g., Centers for Disease Control and Prevention), it is unclear if funding for birth defects surveillance and research (and other public health priorities) will be adversely affected. Further, many birth defects surveillance systems are housed within larger governmental agencies that will also be shifting some degree of focus to COVID-19 surveillance. Significant diversion of staff, equipment (e.g., laptops), and other resources to surveil and investigate COVID-19 could affect birth defects surveillance capacity, depending in part on the length of time these diverted resources are needed. For example, redirection of resources without replacement may ultimately lead to difficulty for programs to meet deadlines, train additional staff, and manage the heightened workload for an extended period of time. However, it is also possible that the response to COVID-19 might serve to provide supplemental resources (e.g., new funding opportunities, data sets, and/or infrastructure) to surveillance programs that would additionally enhance ongoing birth defects efforts.

4 | EPIDEMIOLOGIC CONSIDERATIONS

Systemic differences in over- or under-reporting of birth defects exacerbated by the COVID-19 response will present challenges for analysis and interpretation of the epidemiological data captured by programs. For example, as a result of the facility/provider constraints and patient concerns mentioned above, ascertained cases most in need of health care (i.e., those with more severe birth defects) may be over-represented in birth defects registries. Overrepresentation of severe defects among cases may influence results of epidemiologic analyses, and findings of analytic investigations may be less generalizable to cases with less severe defects. For example, overrepresentation of severe defects would have major implications for outcomes-based studies (e.g., survival analyses). Further, as a result of issues related to changes in the availability and access to care during the pandemic, certain population subgroups may be disproportionally affected (e.g., lower income, lower education, uninsured/under-insured, and certain race/ethnicity groups), particularly in the long-term. Errors in case ascertainment and abstraction (e.g., related to increasing workload or diversion of resources) also may be present in data collected during the outbreak and lead to information biases. Further, because many birth defects surveillance systems conduct abstraction and data quality a year or two after birth (e.g., to allow time for documentation of birth defects diagnoses during medical encounters throughout the first year of life), potential effects of the COVID-19 pandemic may not become evident in our available data for some time, and it may be more difficult to develop strategies to mitigate the impact so far after the fact.

5 | OPPORTUNITIES FOR MITIGATING THE IMPACT OF COVID-19

The COVID-19 pandemic presents opportunities for healthcare systems to adapt in ways that may increase long-term accuracy and efficiency. Birth defects surveillance programs are not unique with this regard, and should embrace the challenge of implementing strategies (e.g., optimizing remote capacities) to better function in resource-constrained or nontraditional public health environments. Rapid birth defects ascertainment programs, interoperability of EMR, and other innovative uses of supplemental data sources (e.g., Medicaid) may be helpful for quickly identifying changes, since complete data for 2020 deliveries may not be available in some birth defects registries until 2022 or later.

Data management and analytic strategies will be important tools for identifying and reducing the potential negative effects of COVID-19 in birth defects surveillance data. For example, consideration of changes in the observed prevalence and severity of specific birth defects before, during, and after the COVID-19 pandemic may help to better understand data quality issues. Likewise, changes in the distributions of maternal characteristics and descriptive epidemiology of specific defects (e.g., maternal race/ethnicity, age, education, and other factors) may also help identify potential concerns about data quality. These management techniques will critically rely on the comprehensive collection of these variables at present. Analyses within and across specific population subgroups (e.g., urban versus rural maternal residence) may lead to further insights about differences in data quality between subgroups.

If major differences are ultimately identified during the COVID-19 pandemic period, it would be beneficial to consider excluding cases conceived and/or delivered during this period from certain analyses. Researchers

may alternatively consider adjusting for time period or conducting sensitivity analyses (e.g., stratifying by time period) if the data set of interest is inclusive of pre- and post-COVID-19 cases. Because effects (i.e., information bias) may vary across defects, medical facilities, maternal residential geography, and other factors, specialized analyses may be required to better understand the impact on the data and to what extent any identified impact may result in a meaningful change in the interpretation of the results, perhaps on a case-by-case basis for each new project. A qualitative process evaluation, including interviews with birth defects registry medical record abstractors, quality control experts, clinical consultants, and other partners, might provide further important insights regarding the ways in which birth defects registry data have been impacted by COVID-19. In fact, surveillance programs may consider vigilant documenting of any operational changes, and may also consider collecting supplemental information during the pandemic period that would allow for better future investigation of the potential influences of the pandemic on the program (e.g., abstraction dates/processes and qualitative metrics related to abstraction challenges). Further, it may be helpful to discuss and identify clinical challenges with our clinical partners early during this phase, especially for programs that rely on reporting of case identification from clinicians who may have less capacity to do so during the pandemic (e.g., passive surveillance systems).

6 | CONCLUSIONS

Like so many other sectors of public health and medicine, birth defects surveillance programs are being forced to reorganize and respond to a changing landscape. Although the situation creates obstacles, opportunities for improvement of existing activities and implementation of new techniques may arise in the wake of COVID-19, such as organizational and methodological changes in surveillance data collection and reporting. New opportunities for collaboration and sharing experiences across birth defects registries will likely arise. The crisis has especially highlighted the need for continued partnership and increased communication between surveillance programs and the institutions from which their data come from in order to better serve the communities in which they reside.

Birth defects surveillance systems will likely innovate to identify a range of new resources and strategies. Our collective response to Zika virus in 2015, which imposed different challenges to surveillance programs, resulted in improved capacity to build infrastructure to more rapidly ascertain cases of specific birth defects. The ongoing response to COVID-19 will hopefully similarly shape the future infrastructure and direction of birth defects surveillance. Any new processes will likely be highly variable and specific to the needs of the individual country or healthcare network, but may lead to advancements in scope, efficiency, and accuracy. The healthcare conditions created by COVID-19 are rapidly evolving and creating both challenges and opportunities in birth defects surveillance at every level for clinicians, staff, and patients. Identifying potential issues early will allow for data collection modifications and analytic techniques to be implemented as necessary and perhaps lead to innovative solutions moving forward. By working with our governmental, scientific, and stakeholder partners, we can continue to work toward both COVID-19 and birth defects prevention, concurrently and effectively.

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